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Mastery, functional disability and perceived health status in patients with multiple sclerosis

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Background and purpose: Multiple sclerosis (MS) is a chronic disease that is difficult to predict and to cope with. Mastery refers to the extent to which patients see themselves as being in control of the forces that affect their lives. It may play an important role in perceived health status and well-being. The purpose of this study was to clarify whether mastery is associated with functional disability and perceived health status in MS patients and how such an association might function. *Methods:* Two hundred and three MS patients completed the Short-Form-36 Health Survey as well as the Pearlin–Schooler Mastery Scale. Functional disability was assessed using the Kurtzke Expanded Disability Status Scale. Hierarchical multiple linear regression analyses were performed on the data from two MS age groups: < 45 and ≥45 years of age. *Results:* Functional disability was negatively associated with perceived physical health status in both age groups and with perceived mental health status in younger age group. Mastery was positively associated with perceived health status in older age group. *Discussion:* The findings confirm that mastery might be helpful for older MS patients. Education strategies for MS patients aimed at personal empowerment for the maintaining of physical and mental well-being may be important.

Introduction

Multiple sclerosis (MS) is a chronic disease that follows an unpredictable course as it affects the central nervous system. It is the most common cause of neurological disability in young adults with the incidence of symptoms appearing and varying over time [1,2]. Functional disability has been associated with restricted participation in employment, educational opportunities, interpersonal relationships and leisure-time activities for MS patients [3–5]. A socio-medical model of the disablement process explains how chronic and acute conditions affect the functioning of specific bodily systems, physical and mental activities and the activities of daily life. Personal and environmental factors can speed up or slow down the disablement of patients [6,7].

Disablement status has been found to be reflected in the perceived health status of the chronically ill [6,7], and several studies have also investigated this relationship in patients with MS. With the progression of a disability, it is primarily physical functioning that shows a decrease in perceived health status. As previous studies have reported, a higher level of functional disability has negative consequences on perceived health status in MS patients [5,8,9]. Quantifying the clinical impact of MS on perceived health status can be assessed in clinical trials and in everyday practice to optimize individual patient care [10–12].

Mastery as a part of a patient's self-concept could be useful in achieving better health status. Mastery refers to the extent to which people see themselves as being in control of the forces that significantly affect their lives. It is considered as responsive to the conditions of people's lives [13]. Mastery is studied from the perspective of ways of coping with a progressing chronic disease [14,15]. The positive effect of higher mastery on physical and mental health in disabled elderly persons has been shown in many studies [16–18]. Low mastery has been identified as a risk factor for functional decline

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in older people in The Netherlands [19]. Mastery, or perceived control in elderly persons, is crucial for maintaining functional ability in later life. It makes a unique contribution to changes in functional disability [19,20].

Lower levels of mastery are associated with greater depression. Mastery shows a significant interaction with functional disability in predicting depression and it has a protective role with regard to mental health in older people. Similarly, mastery and perceived health status of senior adults with orthopaedic disabilities have been studied, with mastery correlating positively with positive health perceptions and relating inversely to depression. Higher levels of mastery buffer against the anxiety associated with greater impairment in physically disabled adults as well [16,17,21].

There is inconsistency in the findings about the associations between age and mastery. Increasing mastery with increasing age may reflect the attainment of personal and institutional resources that contribute to greater mastery [17,22]. However, there are also studies that report decreasing mastery with increasing age [16,17,22,23]. Functional disability is seen as being more related to mastery for older people because it occurs in the context of other negative changes. Some studies have found the influence of disability on mastery to be affected by age and their interaction differs across age groups [14,23,24]. Older and younger MS patients may differ in coping strategies in their lifetime; therefore, there is an assumption that they differ in self-concept, including mastery.

Within the context of this study, age is an important factor that might play a role in the perception of health, disability and mastery. To improve functioning or just to stop the decrease in functional disability, different therapeutic strategies are used in MS patients. New disease-modifying drugs are the most commonly used approach [25]. In Slovakia, these disease-modifying drugs were accessible predominantly for MS patients aged 45 year or younger, suffering mainly from relapsing-remitting or secondary-progressive clinical courses [26].

The study was conducted because, thus far, little research has been done with MS patients regarding the associations between mastery, functional disability and perceived health status. Younger MS patients (<45 years of age) might differ in the evaluation of mastery and their health status from that of older MS patients (≥45 years of age). The aim of this study was to clarify whether mastery is associated with functional disability and perceived health status in MS patients and how such an association might function. We expected better mastery and less functional disability to be associated with higher perceived physical and mental health status in MS patients even when controlled for relevant sociodemographic and clinical variables. We also expected that the relationship between mastery and functional disability, with its associations to perceived physical and mental health status, would differ between younger and older age groups of MS patients.

Methods

Patients

The sample consisted of MS patients from the eastern part of Slovakia. Data were collected from December 2003 to January 2006. MS patients from neurology outpatient clinics and members of MS clubs were included in the study. Outpatient clinics were addressed and MS patients were recruited from those who were eligible to participate. First, questionnaires, invitation letters and written informed-consent forms were sent to the participants' homes by postal mail. After two weeks, a trained interviewer spoke with the MS patients personally in the neurological outpatient clinic. A neurologist then carried out neurological examinations immediately after the interview. These examinations were done by the same neurologist for all patients. One phone call to arrange one more interview was made to those who did not come.

Out of 405 adult MS patients addressed, 214 patients responded and returned the questionnaires (a crude response rate of 52.8%). From these, 11 patients were excluded because of low MMSE or other exclusion criteria. Finally, 203 were included in the study (for an effective response rate of 50.1%; males 35.7%, females 64.3%). There were no differences between the non-responders and the participants regarding gender. A significant difference was found in age ($P < 0.05$); the non-responders (mean age 45.1 ± 10.5 years) were significantly older than the participants (mean age 38.3 ± 10.6 years).

During the interview, patients completed several self-reporting questionnaires and went through physical examinations on a voluntary and anonymous basis. Socio-demographic data including gender, age, marital status, living situation, education level, employment status, family life and disease history were derived from the interview. Mastery and perceived health status were obtained from the questionnaires. Clinical data, including functional disability, disease duration and clinical course were assessed by the neurologist, who was the same for all outpatient clinics. The duration of MS was assessed during the interview and neurological examinations by the same neurologist and compared with data in the patient's medical file. The framework of formal procedure of translation and adaptation of

questionnaires to the Slovak language was respected. Questionnaires were translated from English into Slovak, and then the Slovak version was translated back into English and compared with the original version. Measures were tested in a pilot study with 10 MS patients. Exclusion criteria were as follows: non-Slovak-speaking patients, cognitive impairment determined by a Mini-Mental State Examination (MMSE) score of < 24 [27], history of psychiatric or medical conditions affecting the outcomes of the study and pregnancy. In MS, pregnancy has been a matter of controversy for a long time. Pregnancy can modify the clinical course of disease with a reduced relapse rate, or on the other hand, can cause an increased relapse rate after delivery [28,29]. Symptoms like pain, fatigue, anxiety or less participation in daily activities may occur during pregnancy and are similarly described in MS patients. The responses may thus misrepresent perceived health status and may change the study outcomes in women with MS.

Ethics

Each patient provided a signed informed-consent form before participating in the study. The local Ethics Committee approved the study.

Measures

The Kurtzke Expanded Disability Status Scale (EDSS) is based on the neurological testing of functional systems: pyramidal, cerebellar, brainstem, sensory, bowel and bladder, visual, mental and 'other' [30]. Each functional system is graded to the nearest possible grade, where 0 means normal grade, 6 means loss of function and 'V' indicates an unknown abnormality. Disability caused by MS is graded on a continuum from 0 (normal neurological examination) to 10 (death caused by MS) [30]. This measure, with its widespread use, remains the most frequently-used scoring system in MS in neurological practice [25]. It belongs in the category of physician-oriented measures, as information is based on an objective neurological examination, which, in this study, was performed by the same neurologist on all respondents.

The Short-Form-36 Health Survey (SF-36) was originally designed as a generic indicator of health status for use in population surveys and evaluative studies of health policy [31]. The SF-36 consists of eight dimensions, which can be summarized into two health summary scales to measure those eight dimensions. First, the physical health summary scale contains four dimensions: (i) physical functioning (ten items), (ii) physical role (four items), (iii) bodily pain (two items)

and (iv) general health (five items). Secondly, the mental health summary scale also contains four dimensions: (i) vitality (four items), (ii) social functioning (two items), (iii) emotional role (three items) and (iv) mental health (five items). In addition, one question covers changes in health status over the past year (one item) and the study includes general health perceptions (five items). All item scores are coded and transformed into a scale from 0 (poor health) to 100 (optimal health). Higher scores on the physical and mental health summary scales indicate better functioning [31,32]. Cronbach's alpha for the total score in the present research was 0.93; for the physical health summary scale, it was 0.89 and for the mental health summary scale 0.89.

The Pearlin–Schooler Mastery Scale (PMS) measures the global sense of personal control [33]. It consists of seven items in which high scores represent a strong sense of mastery. Patients responded on a five-point Likert scale about the extent to which they agreed (5 = strongly agree) or disagreed (1 = strongly disagree) with statements such as 'I can do just about anything I really set my mind to' and 'I often feel helpless in dealing with the problems of life'. A PMS score ranges from 7 to 35, with higher score reflecting greater mastery. The PMS was applied to a sample of MS patients providing information about its validity ($r = 0.73$) [34]. In the present study, Cronbach's alpha for this measure was 0.75.

Statistical analyses

To examine the relationships between mastery, functional disability and perceived health status, the following steps were taken. First, mean scores, standard deviations and ranges of scores were calculated for all variables. Secondly, Pearson's correlations were used for testing the associations amongst socio-demographic factors, disease duration, functional disability, disease course, perceived physical and mental health status and mastery. Third, hierarchical multiple regression analyses with the 'enter method' were performed to identify how much of the variance of the dependent variable (SF-36) may be explained by sociodemographic factors, functional disability and mastery. The block of sociodemographic variables (age, education, gender, marital status and employment) were entered into the equation at Step 1; functional disability (as measured by the EDSS) was entered at Step 2 and finally, mastery was entered into the equation at Step 3 in the total sample (Table 3). In the groups of younger (< 45) and older (≥ 45) MS patients, functional disability (as measured by the EDSS) was entered at Step 1 and mastery was entered into the equation at Step 2 separately (results presented in Table 4). Hierarchical multiple

regression analyses were performed for the total sample (results presented in Table 3) as well as for samples of younger (<45) and older (≥45) MS patients (results presented in Table 4). The age cut-off of 45 years was based on accessibility to disease-modifying drugs in this sample [26,35].

Data were analyzed using the Statistical Package for the Social Sciences 12.0 (SPSS Inc., Chicago, IL, USA).

Results

Basic description of the sample

A basic description of the sample is given in Table 1 ($n = 203$). In general, the MS responders were of middle age (mean age 38.3 ± 10.6 years), consisted of more women than men (64.3% females), were married or cohabiting (64.1%), had secondary education (51.7%) and were not employed (65.5%).

Almost three quarters of the sample had the relapsing-remitting course (72.3%). The average duration of disease, measured as time from diagnosis, was 5.3 ± 4.1 years (range 0.5–15.5). The mean EDSS score was 3.0 ± 1.5. The physical health summary scale mean score was 48.6 ± 20.2 and the mental health summary scale mean score of SF-36 came to 57.0 ± 16.1. The mean score for mastery was 21.5 ± 5.5 (Table 1).

The subgroup of the younger MS patients (<45 years old; mean age 32.6 ± 6.9 years; 69.0% female) had predominantly the relapsing-remitting course (82.7%) with a mean duration of illness of 4.7 ± 3.7 years. The subgroup of older MS patients (≥45 years old; mean age 50.8 ± 4.9 years; 53.1% female) had the relapsing-remitting course in 48.4% and the mean duration of illness was 6.8 ± 4.4 years. The main study variables with means and standard deviations for the two age groups of MS patients are described in Table 1.

Correlations between study variables

Table 2 demonstrates the significant cross-sectional relationships between variables. EDSS and clinical course are strongly positively correlated with disease duration; EDSS is strongly negatively correlated with physical and mental health status in MS patients. Disease duration and clinical course are negatively

Table 1 Description of the study sample and two age groups of MS patients: <45 years of age and ≥45 years of age

Variable	Total sample ($n = 203$) n (%) or mean ± SD	<45 age group ($n = 139$) n (%) or mean ± SD	≥45 age group ($n = 64$) n (%) or mean ± SD
Gender			
Women	130 (64.3)	96 (69.0)	34 (53.1)
Age	38.3 ± 10.6	32.6 ± 6.9	50.8 ± 4.9
Marital status			
Living alone/single	73 (35.9)	61 (43.9)	12 (18.8)
Married/cohabiting	130 (64.1)	78 (56.1)	52 (81.2)
Living situation			
Own apartment/house	126 (62.1)	49 (35.3)	45 (70.3)
Education			
Elementary	58 (28.6)	38 (27.3)	20 (31.3)
Secondary	105 (51.7)	75 (53.9)	30 (46.9)
University	33 (16.3)	26 (18.7)	7 (10.9)
Employment status			
Employed/studying	69 (40.0)	53 (38.1)	16 (25.0)
Not employed	133 (65.5)	86 (61.9)	47 (73.4)
Disease duration	5.3 ± 4.1	4.7 ± 3.7	6.8 ± 4.4
EDSS	3.0 ± 1.5	2.7 ± 1.5	3.7 ± 1.3
Clinical course			
Relapsing-remitting	146 (72.3)	115 (82.7)	31 (48.4)
Secondary-progressive	21 (10.3)	6 (4.3)	15 (23.4)
Primary-progressive	35 (17.2)	17 (12.2)	18 (28.1)
SF-36			
Physical[a]	48.6 ± 20.2	53.4 ± 19.9	37.6 ± 16.4
Mental[a]	57.0 ± 16.1	58.7 ± 16.6	53.1 ± 14.2
Mastery	21.5 ± 5.5	21.2 ± 5.6	22.0 ± 5.3

EDSS, Expanded Disability Status Scale; SF-36, Short-Form-36 Health Survey; [a]Higher scores indicate 'better functioning'.

Table 2 Pearson's correlations between the studied variables

	r	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.
1.	Age	–										
2.	Education	ns	–									
3.	Gender	ns	ns	–								
4.	Marital status	−0.42**	ns	ns	–							
5.	Employment	0.14*	0.42**	ns	ns	–						
6.	Disease duration	0.29**	ns	ns	ns	0.20**	–					
7.	EDSS	0.33**	−0.21**	−0.15*	ns	0.31**	0.36**	–				
8.	Clinical course	0.35**	ns	ns	ns	0.19**	0.32**	0.63**	–			
9.	Physical SF-36	−0.43**	0.24**	ns	0.19**	−0.35**	−0.23**	−0.53**	−0.38**	–		
10.	Mental SF-36	−0.25**	0.18*	ns	0.19*	−0.21**	ns	−0.30**	−0.27**	0.64**	–	
11.	Mastery	ns	ns	ns	ns	ns	ns	ns	ns	ns	0.18*	–

Coding: Marital status 1 = married/cohabitating, 2 = living alone/single; Employment 1 = employed/studying, 2 = not employed; Gender 1 = men, 2 = women; ns = no significance; *$P < 0.05$; **$P < 0.01$.
For abbreviations see Table 1.

associated with the physical summary scale. Regarding the mental summary scale, clinical course is negatively correlated with this scale, while mastery positively correlated with it. Mastery appeared not to be associated with the main variables of interest, EDSS and the physical health summary scale in the total sample (Table 2). When comparing the correlations in younger and older MS patients, mastery was significantly associated with EDSS ($r = -0.33$; $P \leq 0.01$), clinical course ($r = -0.34$; $P \leq 0.01$), physical summary scale ($r = 0.39$; $P \leq 0.01$) and mental summary scale ($r = 0.33$; $P \leq 0.01$) only in the older MS age group. Significant relationships between EDSS and the physical health summary scale in the SF-36 were found (Table 2; $r = -0.53$; $P \leq 0.01$).

Physical health status

In the whole group of MS patients, 41.6% of the variance in perceived physical health status was explained by a model consisting of age, gender, marital status, education, employment, EDSS and mastery ($P \leq 0.001$). EDSS was the strongest variable associated with perceived physical health status in these patients ($\beta = -0.34$; $P \leq 0.001$) (Table 3).

Table 4 presents the explained variance of the model consisting of EDSS and mastery in the age groups < 45 years and ≥45 years. The larger variance of perceived physical health status was explained in the age group ≥45 years (adjusted $R^2 = 0.24$; $P \leq 0.01$). EDSS was significantly associated with perceived physical health status in both age groups. Mastery was significantly associated with perceived physical health status in older MS patients (≥45 years old), but not in younger ones (< 45 years old) ($\beta = 0.31$, $P \leq 0.01$; $\beta = 0.01$, not significant; respectively).

Table 3 Hierarchical multiple regression analysis: sociodemographic variables, EDSS and mastery on perceived physical and mental health status

	Physical health status SF-36		Mental health status SF-36	
	Adjusted R^2	Beta	Adjusted R^2	Beta
1st step				
Age		**−0.33***		**−0.25**
Education		0.11		0.06
Gender		−0.06		−0.10
Marital status		0.03		0.06
Employment	32.0	**0.14*	12.7	0.14
2nd step				
EDSS	41.9	**−0.34***	13.5	−0.08
3rd step				
Mastery	41.6	0.01	14.6	0.13

Adjusted R^2 are displayed; significant values are displayed in bold; *$P < 0.05$; **$P < 0.01$; ***$P < 0.001$.
For abbreviations see Table 1.

Mental health status

With regard to perceived mental health status, 14.6% ($P \leq 0.001$) of the variance was explained by a model consisting of age, gender, marital status, education, employment, EDSS and mastery in the total sample (Table 3).

Table 4 presents the results of the analyses for two age groups. The examined model consisting of EDSS and mastery explained the largest variance in perceived mental health status in the group of MS patients ≥45 years (adjusted $R^2 = 0.12$; $P \leq 0.01$). EDSS appeared to be a significant variable related to perceived mental health status in younger MS patients (< 45 years old), but not in older ones (≥45 year old) ($\beta = -0.19$, $P \leq 0.05$; $\beta = -0.19$, not significant; respectively). In contrast, in the group of older MS

| | Age groups | | | |
| | < 45 | | ≥45 | |
	R^2	Beta	R^2	Beta
Physical health status SF-36				
1st step				
EDSS	**0.22*****	**−0.48*****	**0.17****	**−0.43****
2nd step				
EDSS	**0.22*****	**−0.48*****	**0.24****	**−0.34****
Mastery		0.01		**0.31****
Mental health status SF-36				
1st step				
EDSS	**0.03***	**−0.19***	**0.06***	**−0.27***
2nd step				
EDSS	**0.04***	**−0.19***	**0.12****	−0.19
Mastery		0.15		**0.28***

EDSS, Expanded Disability Status Scale; adjusted R^2 values and Beta values are displayed; significant values are displayed in bold; *$P < 0.05$; **$P < 0.01$; ***$P < 0.001$.

patients, mastery was significantly associated with perceived mental health status ($\beta = 0.28$; $P \leq 0.05$) (Table 4).

Discussion

This study aimed at examining the association between mastery, functional disability and perceived health status in MS patients. Better mastery and less functional disability were expected to be associated with better perceived physical and mental health status.

The results provide support for the hypothesis that the negative association between functional disability and perceived health status was significant. This finding is in line with existing studies on functional disability and perceived health status [6,11,36]. Our results also show that better mastery is associated with a higher perceived physical health status and perceived mental health status. These results are in line with previous findings in other chronically disabled patients, where mastery predicts rising levels of psychological well-being and quality of life amongst these people [15,37].

Although mastery was not correlated with the variables of interest when examining the sample as a whole, when looking at the specific age groups, mastery was associated with perceived health status for the older participants, but not for the younger ones. Multiple linear regression analyses performed separately for the two age groups clearly showed that mastery explained more variance in the perceived physical and mental health status in older MS patients than in younger ones. Similarly, in a study by Forbes, mastery was signifi-

cantly related to health status and perceived health in a group of elderly community-dwelling people [18]. For the younger age group, functional disability appeared to be the most important variable for explaining variances in the physical health status of MS patients.

The SF-36 as a generic indicator allows comparing the health status of chronic patients with different conditions and can be related to the prognosis of disease and intervention outcomes [31,38]. The outcomes of the perceived physical and mental health summary scales in the present study are comparable to the findings of other European studies focusing on health status in MS patients. Perceived health status in MS patients inevitably worsens because of MS, and thus the scores in the dimensions of perceived physical and mental health status are low [3,5,10].

The findings show that functional disability is positively associated with the age of MS patients. This is a consequence of MS being a progressive chronic disease, although a direct association between functional disability and mastery was not confirmed. To summarize the results, worse functional disability, higher mastery and worse perceived health status in the older age group than in the younger one could suggest that the progress of MS should be taken into account. Patients may adapt to the conditions of their lives with MS, and older MS patients perhaps know better what to expect and how to behave in response to possible deterioration of their health status. They may undergo a psychological adjustment process enabling them to cope with impairment [39]. This adjustment is important for coping with the disease, for the feeling of having control of one's life.

Our findings confirm that mastery might be helpful for older persons with MS. Individuals with greater mastery are more probably to use preventive care, have good health behaviours, seek treatment early and use health services properly [17,40,41]. Patients with a strong self-concept (high self-esteem and mastery) may be more probably to 'see the light at the end of the tunnel' and consequently predict positive outcomes for themselves despite their current problems [42].

Some limitations should be noted in the generalisation of our results. MS patients participating in this study were significantly younger than the non-responders. We may assume that the non-responders were a proportion of the oldest MS group, with the longest disease duration and possibly the most affected group, which might have prevented them from participating. The results cannot be therefore extended and generalized to the whole MS population as the oldest group of MS patients was missing from this study. Also, the existence of unique features of the national health care system may lead to a certain limitation of

this study. In particular, the inaccessibility to disease-modifying drugs in MS patients over age 45 may lead to differences when outcomes are compared with patients from other countries. In addition, the outcomes of this cross-sectional study cannot be causally determined. Mastery and its stability is a subject of controversy. To clarify stability or changes in mastery over time in MS patients, a longitudinal study design is needed. Longitudinal data are needed to further unravel the complex interplay between functional disability, perceived health status and mastery in MS patients.

The clinical importance of this study is that older patients possessing higher levels of mastery have a greater likelihood of perceiving mental health status more positively than those who are less disabled but have lower mastery. This may be assumed to involve individuals' mastery in making personal choices and deciding the level of participation in health care and society [22]. In the end, their quality of life might be better.

Clinical implications

The results of our analyses suggest that mastery can be a variable important for perceived mental health status, especially in MS patients aged 45 years and over. The consequences for clinical practice are aimed especially at the group of older MS patients who are less probably to experience a significant improvement of their health status. On the other hand, these patients report more physical and psychological health complaints. Therefore, more intensive medical and psychological attention should be paid mainly to older MS patients. Education strategies for groups of MS patients, provided by psychologist or trained nurses and focused on personal empowerment for maintaining physical and mental well-being in the face of MS, may be important. A collaborative strategy during group psychotherapy may allow MS patients to share their knowledge regarding how to influence attitudes and to improve physical and mental health. MS patients may effectively mobilize personal resources better and cope with the disease and thus may perceive their mental health as better with a higher level of mastery. Hence, there is a challenge for future research to measure self-efficacy and social support like other related variables associated with perceived health status in MS patients. Neurologists' education and counselling supporting the coping strategies of MS patients are essential for good patient management.

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Disclosure

The authors declare that they have no conflicts of interest.

Author contributions

Data collection: M. Krokavcova, M. Gavelova; Manuscript writing: M. Krokavcova, I. Nagyova, J.P. van Dijk, J. Rosenberger, M. Gavelova, Z. Gdovinova, J.W. Groothoff; Design of study: M. Krokavcova, I. Nagyova, J.P. van Dijk, J. Rosenberger, B. Middel, J.W. Groothoff; Statistical analysis: M. Krokavcova, I. Nagyova, J. Rosenberger.

All authors contributed to the structure, revision and writing of the article.

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